# THE PHANTOM PHENOMENON: ITS USE AND DISUSE\*

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Individuals who have undergone deafferentation because of lost body parts or because of transverse myelopathy or total limb denervation almost invariably report an awareness of the deafferented part. This is commonly referred to as the "phantom phenomenon."

The awareness could be functionally integrated by the patient as a result of appropriate functional challenge. The lack of such challenge, by disuse, tends to enhance abnormal perception of the phenomenon. Current knowledge of the phantom phenomenon will be considered in development of a functional approach for clinical use. Extensive clinical and neurophysiological studies and abundant hypotheses are focused on mechanisms and control of complications.<sup>1-8</sup> This paper deals with prevention of such complications by enhancement of function.

#### ORIGIN

Because the phantom phenomenon is universal, the logical question to be asked is how and when it began. The answer is that it has always been present and probably a structural basis for the phantom experience is encoded in the DNA. We are born with a full-blown potential for imaging body parts. An immediately available cohort whereby to establish the credibility of this concept are those individuals born without limbs. For many years it was believed that the phantom phenomenon did not occur in congenital amputees and in a high proportion of children who underwent amputation before the age of eight.<sup>9</sup> The implication was that feedback from the periphery of sufficient duration and intensity was absolutely essential for its formation. This idea has been found wanting. In our laboratory Weinstein and his co-workers established the existence of

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phantom limbs in 18 out of 101 children with congenital aplasia.<sup>10</sup> Single cases have been reported by others to confirm this finding.<sup>11-13</sup> That it had not been more frequently observed would be puzzling were it not that physicians are least prone to ask about something that they cannot see, feel, hear, or smell.

It would be going too far to say that feedback from the periphery is not essential for the formation of the phenomenon, because the part in place is not the only locus of feedback. The difference between the low incidence of the phenomenon in congenital amputees and the almost universal incidence in acquired amputations may very well rest on the multiple loci and variations in duration and power of feedback from such loci.

#### CONTROL MECHANISM

It is now almost universally accepted that the control mechanism of the phantom phenomenon lies at the highest levels of the central nervous system. Some have located image formation in the topographical representation in the cerebral cortex. The distorted picture of man in the cerebral homunculus as proposed by Penfield<sup>14</sup> seems to correlate with the intensity of the perceived image of the ablated part. Thus, the foot, thumb, and hand are proportionately over-represented in the cortex and tend to be perceived more vividly peripherally. In contrast, proximal perceptions are weaker in the image and these parts are under-represented in the cortex.

On occasion, insults to or near the suspected sensory cortical area such as vascular and surgical lesions, epileptogenic foci, or electroshock have been reported either to ablate, to heighten, or not to influence the phenomenon. That such things do not happen consistently is a problem that perhaps can be explained by the enormous variations in and extents of lesions that can occur even when peripheral manifestations of stroke may seem to be much alike. Most often, strokes occurring after amputation do not change the phantom phenomenon except that in a small percentage of cases it is ablated. Appenzeller and Bicknell found that lesions affecting the contralateral parietal lobe may abolish the phantom experience but only when there was also loss of other sensation from the affected side of the body. In addition, the representational cortex does not act as a discrete control but in association with activity at other levels of the brain.

#### COUPLING AND UNCOUPLING

If the ability to image body parts is central in origin and is always

present, it must be present both before and after amputation or deafferentation. The key concept is that it does not arise de novo after loss of peripheral signals from the involved or ablated body part. It merely may tend to become uncoupled in terms of change of position and sensitized in terms of perception. To keep the image in place requires other appropriate afferent signals. Fusion is the term applied to the condition of the image in the place where it should be. 19-20 Coupling is a better term because there is no more adequate way to describe its opposite than uncoupling. As we shall see, despite coupling being under central control, the periphery and center form an indivisible unit in maintenance of body image and in the forms and functions it assumes. Amputation and deafferentation free the image from the kind of perception and even of the kind of movement ordinarily dictated by signals from the intact part. This has been confirmed by studies of Melzack and Bromage on experimentally produced phantom phenomena.<sup>20</sup> They showed that complete blocks of the brachial plexus can uncouple the image from the part, because the image then can move but the part cannot. Individuals on whom this experiment was done were not aware of the position of their limbs when they reported their movements and were astonished when they saw the difference in locations of the inert limbs and their perceptions of where they were. A visual cue was sufficient to produce immediate coupling. We are aware of the difficulties of individuals whose upper extremities have been surgically deafferented for one reason or another: an arm almost useless in the dark, clumsy at best in the light, but retrainable for adequate function by the consistent use of visual cues.

# Afferent Influences

Our previously expressed idea of the effect of peripheral feedback from other than the limb itself upon the coupling phenomenon now comes into focus. Visual signals are almost as powerful and may be one reason for the development of phantom phenomena in congenital amputees. It would be interesting to know the incidence in blind congenital amputees. The addition of visual signals does not exhaust all potential for afferent feedback. There is, for instance, the stump itself. Peripheral nerve trunks tend to be caught up in the tissues of the stump. Terminal attachments may not be ordinarily hypersensitive, but they may respond to tapping by a momentarily vivid representation of the ablated area that they once innervated. This is usually nothing more than a heightened perception of a

part already being experienced. Mediation of such sensory distribution can only be based on afferents routed to the central mechanism. In addition, Teuber demonstrated that, following amputation of the lower extremity, the end of the stump slowly develops more sensation than its intact counterpart and equal to the foot on the opposite side as tested by two-point discrimination.21 This work has been extended by Weinstein to congenital amputees and to other forms of sensation. 10 The nature of the nervous reorganization responsible for this phenomenon is not understood, but Teuber and his co-workers felt that this was "presumptive evidence for central readjustment which imparts to the stump some of the functional characteristics of the amputated limb." These considerations lead to intriguing possibilities, especially in relation to the stimulating effects of the use of prostheses since the stump itself, following central reorganization, is capable of providing heightened feedback. We now see the wisdom of the modern surgical doctrine of saving the knee and its action. The longer the stump with its increased sensation, together with the proprioceptive and kinesthetic properties of the retained knee, the more likely is the image to remain coupled. The shorter the stump and without the knee the more difficult it is to retain coupling. Over the last decade we have conveyed this principle to our surgical colleagues and the number of unnecessary above knee amputations has decreased significantly. Our experience with training blind amputees tells us that feedback from an adequate stump provides enough cues to aid in functional restoration even without vision. The combination of both can indeed be powerful.

# THE CONGENITAL AMPUTEE

The reason for a low incidence of the phantom phenomenon in congenital amputees still remains to be explained. The group studied by Weinstein et al. consisted of sighted individuals among whom were many with long and even jointed stumps, <sup>10</sup> a combination from which a greater incidence of the phantom should have been expected. However, not all congenital amputees wear prostheses. Some never make the attempt to do so for one reason or another; some are thought to be structurally unsuitable and some discard their prostheses rapidly because they get along better without them. Weinstein's group offered an opportunity to determine whether there was any correlation between wearing a prosthesis early and successfully and the existence of a phantom phenomenon. <sup>10</sup> A correlation was found between the age at which the prosthesis was first fitted and the incidence

of perceived image in that it was significantly higher among patients who began using artificial limbs before the age of seven. The modern approach of beginning prosthetic use within the first six months of life is well supported by this correlation. One of the purposes of this approach is to stimulate the development of a more complete body image by coupling it with the prosthesis. That is exactly the point because function should be much better with a more complete image of self.

## THE FATE OF THE PHENOMENON

Natural images are known to persist in terms of size, of perception of sensation, of movement, and of incorporation into function. At the same time, major disruptions do occur. Shrinkage and telescoping, deformity, abnormal position, unusual sensation, and pain have been extensively reported, but it is not usual to find published descriptions of the nature of management programs in which natural adaptations and major disruptions occur. Attention is usually confined to events in the involved part with little correlation to the restorative effort. While it is true that seasoned observers have found a high incidence of psychopathology in those who suffer abnormalities of the image, it would be a serious error to label the psychopathology as the sole or even major determinant of the difference between natural and pathological images.

#### TELESCOPING

Can the concept of an inherent central image capable of controlling coupling in response to signals from vision, from a long jointed stump, and from the restorative process stand scrutiny when applied to other than the amputee? The concept can be tested in individuals who have sustained complete transections of the spinal cord.

Weinstein has emphasized the identical nature of the phantom phenomenon in amputees and traumatic paraplegics which he so painstakingly delineated.<sup>27</sup> Yet there are differences. First, there does not seem to be any telescoping of the image in paraplegics as has been reported in some amputees. Bors, in his excellent paper on the phantom phenomenon in spinal cord injury, reported that telescoping did not occur in his patients.<sup>6</sup> Second, he also found the phenomenon to be absolutely universal, not just nearly universal as in amputees. The explanation should be obvious in that the individual knows that an amputated limb cannot grow back. The amputee goes through a short period of reactive depression in the early

phase of the restorative process and reestablishes function early, particularly if he had had immediate prosthetic replacement. Patients who go through this ideal process do not experience telescoping. Telescoping is more apt to occur with delay or omission of the restorative process with possible lengthening of the period of reactive depression. A paraplegic can see and touch his limbs and is not at all sure that their function will not return. In this respect, the phantom experience and even its frequent discomforts are looked upon as favorable prognostic signs by patients and all too often by inexperienced physicians. Hope for recovery is stimulated by the movements of developing spasticity. In view of the often longsustained if unreasonable hope for recovery, it is little wonder that persons who see their limbs, sense their presence, and observe their movement often expect the final step of return of voluntary control. Such expectations are too often reinforced by unsuitable human and programmatic environments. Retention of limbs may be insurance against telescoping of image because of visual and tactile feedback, but does not always insure against other abnormal events.

#### FADING

Does the phantom representation of the lost part ever disappear? A very few amputees never report an image in the first place. This has been explained as characteristic of some individuals who tend to deny its existence. However, what is evident is that the intensity of the perception is reported to fade or to diminish with the passage of time. There are a number of possible explanations. First, fading may be one result of reorganization following loss of afferent input, as postulated by Teuber. Second, loss of afferent input is known to diminish the size of involved nervous tissue by retrograde atrophy in the spinal cord. That this process may have some effect on more proximal neurones is a strong possibility since such phenomena occur in other parts of the nervous system, such as disappearance of cells in the lateral geniculate body with lesions of the retina.<sup>23</sup> Sunderland suggested a retrograde degeneration of some neurones and functional impairment of others resulting in instability or malfunctioning at different levels.<sup>5</sup> Finally, the restorative process can redirect an individual's internal preoccupation to the more important consideration of social role. In other words, restoration of function with its attendant development of a sense of wholeness reduces the need to emphasize strangeness and alienation as manifested by abnormalities and intensity of the image. However, there is no clear evidence that the phantom phenomenon ever completely disappears. Even the few who claim such disappearance report its reappearance from time to time in response to a wide variety of stimuli, and some may be able to recall the phantom part by volition

# DEFORMITY AND DISPLACEMENT

There have been many reports of images that are deformed in amputees and of images that are uncoupled and markedly out of place from where they should be in both amputees and paraplegics. Amputees can experience images of traumatic deformities such as painfully dislocated feet due to compound fractures only if they saw the deformities at the times of the accidents which led to the amputations. It is rare for such impressions to be maintained for very long with visual cues, with adequate stumps, and with active programs of restoration. Guttmann has said that marked and massive displacement of the image of body parts in paraplegics, among the most extreme of those reported, are usually associated with positions observed by patients at the times of the accidents.<sup>24</sup> Others have been able to make that correlation definitely in some cases but not in others.<sup>25</sup>

Such information leads to the general concept that the more proximal the level of deafferentation, the greater the tendency for uncoupling and displacement of the image. It is in keeping with the notion that coupling is related to the availability of peripheral feedback, the more sources the better, the more peripheral the better. Best of all is mobilization and integration of all residual sources of peripheral feedback through active and early restorative programs because uncoupling does not long resist the influences of such programs.

#### MEMORY

Another important concept is that of the memory engram. Combined visual and sensory impressions of deformity, displacement, and acutely perceived pain at the times of accidents may leave behind chronically maintained experiences after losses of the parts. An individual with prolonged and severe rest pains due to vascular insufficiency or neuropathy prior to amputation is most likely to continue with the same discomfort long after the amputation. Another interesting way of looking at the idea of the image memory for past events is in individuals with Hansen's

disease.<sup>26</sup> The slow and painless loss of the periphery leaves behind a phantom image of lost parts, contrary to opinions which have often been expressed. In these cases there is no reported evidence of discomfort of any kind but rather of the memory of the chronic painlessness that is characteristic of the disease. Thus, there is a memory for acute and chronic experience with pain and at least chronic experience with painlessness as there is for acute and chronic experience with deformity. The chronic experience with deformity has been reported by individuals after amputation of parts of congenitally deformed limbs. In many of these cases, perceptions of sensory and structural dysfunctions are reversible with the passage of time and with programmatic restoration. It is ultimate function that determines the ultimate result. Frazier and Kolb stated: "Patients with functioning prostheses have normal phantoms whereas those with no prostheses or cosmetic ones show an increased incidence of pain." In this respect, deformity may be added to pain.<sup>27</sup>

#### PHANTOM PAIN

The phantom phenomenon may be a natural and expected consequence of deafferentation but pain is not necessarily such a consequence. There are a number of classifications of the phantom experience but what is evident is that a naturally perceived part and a painful part are at two ends of the same spectrum with all kinds of shadings in between. Perception of a lost limb may vary from that which is entirely like its intact normal opposite counterpart to images that incorporate dysethesias and paresthesias that have been described in profuse detail. At one end of the scale paresthetic images are accepted as modified forms of the normal and present no problem. At the other end, these very same paresthesias are reported to be unacceptably painful in intensity. The point in the spectrum at which these sensations become pain with its attendant suffering is a highly individual subjective experience. In other words, whether discomfort is interpreted as pain and the language used depends largely on the type of individuals with whom we are dealing. In a study of amputees attending the limb-fitting center at Roehampton for the first time, Parkes determined that complaints of persisting pain in phantom limbs were found to be significantly correlated with rigid or compulsively self-reliant personalities, persistent illness for a considerable period prior to and after amputation, and unemployment and retirement.<sup>28</sup> In addition to personality, illness, and social status, other factors may determine interpretation of paresthesias and their intensities.

Deafferentation of the control mechanism itself, incomplete as it may be, could alter its sensitivity according to the well-known phenomenon of denervation hypersensitivity.<sup>29</sup> The more the deafferentation, the more likely is such hypersensitivity to occur. Thus, individuals who have sustained spinal cord injuries have large and consistent incidences of phantom discomfort. It may well be that central hypersensitivity tends to be proportional to the extent of deafferentation.

In spinal cord injury the pain is usually referred to as "central" or "cord" pain. This is often interpreted as meaning that the damaged stump of the cord is the central source. This is much like describing the stump as source in the amputee. That this is not so should be illuminated by failure consistently to relieve pain by surgical intervention at all levels proximal to the stump of the leg or the spinal cord lesion. It would be much more appropriate to equate the discomfort and pain in both the paraplegic and amputee as manifestations of the phantom phenomenon, the difference lying in the difference in extensiveness of deafferentation and therefore in the degree of destabilization of the control mechanism. This equation is reinforced by the fact that paraplegics who later underwent amputation tended to retain unchanged images of the lost parts. We have seen six such cases and Bors reported seven.<sup>6</sup>

Interpretations of the intensity of pain and its meaning to the patient seem to be widely variable as reported by observers. Since this is in the eye of the beholder it is an almost impossible task. For instance, the incidences of pain reported in large groups of amputees have differed from as much as close to 100% to as little as no incidence. The consistency of the phenomenon is not matched by an equal consistency with which pain is said to occur with it. This does not make sense nor does the implication that whether pain appears or not depends upon the surgical technique with which the amputation is done. The formation of painful neuromata is not an answer to this dilemma, otherwise less widely divergent incidences of pain would be evident for there is no sure way to prevent their formation by any surgical technique.

It is true that uncomfortable images are more consistently reported in a large proportion of those who had sustained spinal cord injuries. We shall illustrate the use of the term "uncomfortable" rather than "painful" by relating a personally observed serendipitous "experiment." A number of

years ago, a group of 37 paraplegics were transferred from a spinal cord injury center which was being closed to another center of equivalent population. Of the new arrivals, 35 received doses of narcotics because of complaints of constant phantom pain. The proportion was exactly reversed among the patients of the receiving center. Narcotics were immediately withdrawn, and, except for two patients who had withdrawal symptoms, readiustment to the so-called pain went fairly smoothly. This episode illustrates that the interpretation of the meaning of pain by observers can be very faulty indeed. This is one reason why the ease with which pain is reported in the literature should be looked upon with some degree of reservation unless there is a detailed description of the management process. The foregoing "experiment" involved the important variable of change of therapeutic milieu. Transferred patients came from a center largely custodial in nature and without an adequate program of functional restoration. The usual response of the physician to the complaint of pain was a prescription for narcotics. On the other hand, the center to which they were transferred had an active restorative program and, as a rule, narcotics were deliberately withheld. A related study was done by Weiss. who followed a large group of amputees participating in an active program of restoration of function with prostheses. He undertook the study because of the frequent reports of high incidences of pain in the literature, reports which did not seem to mesh with his experience. Strikingly, phantom pain was not reported by patients in his series.<sup>31</sup>

Our own experience covers more than 2,000 amputees in the last 10 years. Classically described intractable phantom pain has not occurred. Phantom pain of no more than a few weeks duration was the complaint in less than 2% of patients. No patient had pain of sufficient duration and intensity to warrant any kind of intervention, surgical or psychiatric. Natural phantom sensations were reported by all patients who could understand the question. Their characteristics were similar to the description of the natural phantom phenomenon as it appears in the literature. On the other hand, local stump pain was reported by 15% of patients. This pain disappeared spontaneously with passage of time, rare surgical interventions in the stump, and most frequently by corrections of prostheses. A very small number of patients were never completely free of stump discomfort. Thus, there was no significant correlation between stump pain and phantom pain either on a short- or long-term basis. While most amputations were of the lower extremity for complications of peripheral

vascular disease, a significant number of upper extremity amputations (more than 30) and amputations secondary to severe injury (more than 60) precluded the elements of upper extremity loss and trauma as being significant in the formation of the painful state of the phantom.

In our patient population, phantom pain as well as other disorders of the phenomenon (such as telescoping, etc.) has not presented a management problem. Our approach to phantom pain in amputees was and is based essentially on its prevention. Patients are seen by members of the rehabilitation team prior to and immediately following amputation while they are still on surgical services. Patients are told that they would experience phantom sensation and that this was a normal experience. They are reassured that any local discomfort would fade away as the healing process progressed. Whenever possible, a rigid plaster dressing is placed over the stump on the operating table to simulate immediate prosthetic fitting. This prevents excessive swelling and helps to shape the stump. Emphasis is put on maintenance of physical fitness, early preprosthetic training with crutches and temporary prosthesis. Patients are encouraged to look at and to touch their stumps. Supportive counselling, sexual counselling, individually or in groups, including family members, are provided according to patients' needs. In rare cases where functional prostheses are not realistic goals, cosmetic devices are provided. Longterm follow-up is in plemented. In other words, the rehabilitation program starts early, is intensive, and is wide in scope.

On rehabilitation wards, narcotic analgesics are not used for postamputation discomfort. Aspirin and acetaminophen with rare codeine supplements are the main pharmacologic agents. Among the elderly, short-term use of thorazine 25-50 mg. at night is useful for bothersome stump pain associated with uncomfortable phantom sensation. The implication is that reports of the incidence of pain should be related to the programmatic matrix. Unfortunately, this basic principle is uncommonly applied in the pertinent literature. There seems to be abundant evidence that neglect engenders dysfunction as manifested by the disorders which have been discussed. Such disorders seem to be less significant when rehabilitation is complete, intense, and early.

Reports described the phantom pain of upper extremities as more intense than those in the lower extremities.<sup>5</sup> Since the introduction of the myoelectric prostheses in patients with upper extremity amputation, Schmidl's group reported a considerably decreased incidence of phantom pain.<sup>34</sup>

In a direct communication with us, he states, "Up to the present time we have supplied 2,500 amputees with upper limb prostheses and of these about a hundred complained of pains at the beginning. With use of the prosthesis, there was in all cases a considerable diminution of the trouble and in several cases it completely disappeared." We believe that phantom pain is a rare complication due mainly to misuse of the phantom phenomenon as it applies to the functional restoration of individuals who have lost parts, have become paraplegic, or who have undergone deafferentation of limbs. Most attempts to find a pharmacological, surgical, or psychiatric solution have failed because they were inappropriately focused. Rehabilitation centers have developed comprehensive approaches for functional restoration, and it is safe to predict that the painful phantom will fade away as an unsolvable problem.

## SUMMARY AND CONCLUSIONS

The phantom phenomenon has a long medical and literary record. Ambroise Paré first mentioned its existence 425 years ago, and S. Weir Mitchell first named it and superbly described it during and after the Civil War. The medical literature contains a number of important contributions between and since the times of these two men. It seems that every major war generated review and reconsideration. The literature has been largely descriptive and has long taken into account most variations of the phenomenon known today. It also includes repeated attempts to explain the mechanism of its production. It is interesting to note that the topic has fascinated such great literary figures as Herman Melville in *Moby Dick* and Erich Maria Remarque in *All Quiet on the Western Front*, which resulted in interesting and accurate descriptions by lay protagonists in the nonmedical literature.

The puzzle is thus well documented, a documentation that contains overly contemplative, overly introspective, and overly invasive approaches to its solution. These approaches are found wanting because there is no let up in the search for solution. What has been and still is needed is a workable concept of management. As a first step in this direction, it must again be emphasized that the literature, with one exception known to us, has not been particularly clear as to specific environmental matrices in which the phantom phenomenon and its pathologic variants occur. It is essential that prime consideration be given to the environment, internal and external, simply because the phenomenon is a biological process.

Like all such processes, it responds to the adverse affects of disuse and to the constructive effects of use. This implies that the phantom experience is useful for function, a viewpoint that is the direct antithesis of the attitude of the great American psychologist, William James, who stated that "The feeling of the lost foot tells us absolutely nothing which can practically be of use to us. It is a superfluous item in our conscious baggage." 35

Evidence indicates that the central control mechanism is remarkably plastic. It tends to reorganize itself after the insult. During such reorganization it responds to a host of influences. It responds to afferent signals from the stump, from vision, from touch, from joint position, and probably from many other sources. It responds to the memory of the precipitating event. It responds to prior illness and illness after deafferentation. It responds to personality. It responds to social status. Ultimately, it responds to the restorative process.

The restorative process attempts to prevent or to minimize those aspects of disuse that lead to pathological consequences by mobilizing those factors which can be manipulated and which are favorable to the restoration of both physical and psychosocial functioning. Function does not flow from the edge of a scalpel, from inactivity, from drugs, from the psychiatrist's couch, or from the array of rediscovered pain-treating modalities. Only function breeds function. A properly functioning individual is one who has coupled his phantom to his prosthesis and has incorporated it into useful and meaningful day-to-day operation. Exceptions to this working concept will inevitably occur because the restorative process is not a rigid and inflexible formula. However, the earlier, the more intense, and the more complete its application the less likely are the complications of pain and dysfunction.

We believe that a positive and welcoming attitude toward the phantom phenomenon and its incorporation into function will enhance the patient's restoration.

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